Research paper

Disabled adolescence – spaces, places and plans for the future: A case study

Adolescence en situation de handicap – des espaces, des lieux et des plans pour le futur : une étude de cas

Halvor Hanisch*

Oslo University College, Department of Health Sciences, P.O. Box 4, St. Olavs plass, N-0130 Oslo, Norway

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ABSTRACT

Recent theories of modernity, in particular the work of Anthony Giddens, have had a significant impact on youth research. However, Giddens has rarely taken the insights of disability research into account. Similarly, many disability scholars have criticized or even rejected his theoretical framework. Thus, research on disabled adolescents has remained estranged from the mainstream of youth research. This paper aims to show that these two perspectives can be fruitfully combined. This proposition is developed through a case study, which is based on interviews of a disabled 15-year-old girl and her mother. Aspects of spatiality and mobility of the young adolescent are explored in her everyday practices as well as in her dreams and plans for the future. These interviews evidence that the informant's everyday life is marked by disabling barriers in spaces and places; but they also put forward that her practices and plans reveal competence, reflexiveness and complexity. On the one hand, the substance of the interviews suggests that Giddens' "ideal-typical" descriptions of late modernity may be inadequate, at least to the extent that they presuppose an able body in an almost barrier-free environment. On the other hand, the reported spatial practices can be enlightened by Giddens' analyses of

* Kirkeveien 90 d, N-0364 Oslo, Norway.
E-mail address: halvor-melbye.hanisch@hf.hio.no

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"dis-embedding" and "re-embedding". To conclude, we recommend that disability studies integrate, adapt and develop "Giddensian" strands of modernisation theory, rather than dismiss them.

R É S U M É

Les théories récentes de la modernité, et notamment les travaux d'Anthony Giddens, ont fortement influencé la recherche sur les jeunes. Pourtant, Giddens a rarement pris en compte les perspectives des recherches sur le handicap. À ce constat vient s'ajouter le fait que de nombreux chercheurs spécialistes du handicap ont critiqué ou même rejeté son cadre théorique. Les recherches sur les adolescents handicapés demeurent donc déconnectées des recherches générales sur les jeunes. Cet article a pour but de montrer que la mise en rapport de ces deux perspectives peut être féconde. Ce point de vue est développé grâce à une étude de cas qui s'appuie sur les interviews d'une jeune fille de 15 ans en situation de handicap et de sa mère. Ces entretiens abordent des aspects relatifs à l'espace et à la mobilité au travers des pratiques quotidiennes de cette jeune fille, mais aussi au travers de ses rêves et de ses plans pour l'avenir. Ces entretiens mettent en évidence que les activités et les relations sociales de cette jeune fille sont confrontées à des obstacles environnementaux, mais ils montrent également que ses pratiques et ses plans d'avenir font preuve de compétence, de réflexivité et de complexité. Par ailleurs, le contenu des entretiens suggère que les descriptions « d'idéal type » que propose Giddens de la modernité peuvent s'avérer insuffisantes, du moins dans la mesure où elles présupposent un corps parfaitement fonctionnel dans un environnement pratiquement sans obstacle. En outre, il apparaît que les pratiques spatiales rapportées par cette jeune fille peuvent être éclairées par l'analyse de Giddens sur le « déancrage » et le « réancrage » Pour conclure, nous invitons les recherches sur le handicap à intégrer, adapter et développer la théorie de la modernisation de Giddens, plutôt que de la rejeter.

Mots clés :
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> 'It would be very dangerous if the focus of disability studies on oppressive structures resulted in a view of disabled people as powerless or doomed' (Shakespeare and Watson, 1998:24).

Introduction

Recent youth research has increasingly focussed on *plasticity* in social practices. This empirical research is often framed by a certain historical analysis, frequently referred to as modernization theories. The key work in this respect is Anthony Giddens' *Modernity and self-identity: self and society in the late modern age* (1991).

Giddens' work aims at a macro-sociological tendency, i.e., increased social mobility and accelerating pace of institutional and socio-material change, rather than at "grand theory". This increased fluidity of social structures, including an increased unpredictable flexibility of social agency, is termed "dis-embedding", leading on to his general claim that 'modernity is a post-traditional order' (Giddens, 1991:2). As social actions are no less social, the dis-embedding of social agency makes it continuously *re-embedding*. This has several implications on the individual level. On the one hand, 'self-identity becomes a reflexive endeavour'. On the

other, these ("emancipated") 'processes of self-realisation influence global strategies' (Giddens, 1991:5,214).

These "emancipated" social practices are certainly no less social (or less political). Fluid structures are just as important in structuration as traditional ones, and social actions and practices are fully integrated with the institutionalised "rules and resources" we call social structure (Giddens, 1984:xxxi). Rather, the distinction between dis-embedding and re-embedding is "a version of the old distinction between "freedom from" and "freedom to" (Giddens, 1990:156). Relying on his earlier work on structuration, Giddens combines his interest in fluidity and plasticity with a continued emphasis on power and social structures. Hence, Giddens calls these dis-embedded modes of social action *life politics*.

This focus on agency is also evident in Giddens' attempt to 'sketch a phenomenology of modernity' (Giddens, 1990:139). As this attempt is 'first of all' inspired by Merleau-Ponty (Giddens and Pierson, 1998:146), it is necessary to explore how *the body-space relation* may be imagined. It is clear that the late modern subject (according to Giddens) is not only dis-embedded in a social or cultural sense – dis-embedding is also a spatial phenomenon:

> The life-span becomes separated from the externalities of place [. . .] place becomes thoroughly penetrated by dis-embedding mechanisms, which recombine the local activities into time–space relations of ever-widening scope. Place becomes phantasmagoric (Giddens, 1991:146).

Similarly, he seems to imply a "neutral" body – be it as a neutral site of interaction or as a versatile and high-performing 'element of the reflexive project of the self' (Giddens, 1991:218, 99–100). This notion of neutral and versatile embodiment has aroused criticism from disability scholars, who mainly deals with those who (by way of impairment and social exclusion) are positioned as *different*. One of Giddens' most notable critics in this area, the English sociologist Bill Hughes, writes:

> It is quite clear that contemporary sociology has been seduced by metaphors of mobility. The language of fluids and flows, networks and liquid relationships, surfing and scapes, is central to sociologic discourse. [. . .] Disabled people in general and young disabled people in particular do not have sufficient opportunities to 'go with the flow'. In fact 'the flow' is a source of their immobilization (Hughes et al., 2005:14).

There are at least three reasons for this criticism. Firstly, Giddens' concept of the body seems incompatible with the facticity of impairments; 'the problematic reality of biological limitation' (Shakespeare, 2008:238) is hardly phantasmogoric. Secondly, the impaired body is often framed as a stigma – or at least a focal point of staring – making it less suitable for "reflexive projections" of self and identity. Finally, the social and technological requirements in the public space, which Giddens views as facilitating increased mobility in every sense, is the exemplar case of barriers and exclusion in sociological research into disability.

From its foundational phase, the disability studies tradition has contrasted the life of people with impairments with a macro-sociological image of social 'mainstream'. Often, it seems as if this mainstream is described in accordance with Giddens. This is especially the case with research into the lifestyles of young disabled people, as with the psychologist Clare Connors and sociologist Kirsten Stalker:

> at this age leisure and friendship 'happen' either in young people's homes or venues like sporting facilities or shopping centres, neither of which may be accessible to some disabled adolescents and teenagers (Connors and Stalker, 2007:26).

Connors and Stalker appear to attribute to these two arenas (indoors and out of doors) the same function and significance for disabled young people that they would have for others.

This tendency is crucial to the history of social science research into disability, and more specifically, to the history of the social model of disability. UPIAS, which, for instance, defined disability as exclusion 'from participation *in the mainstream* of social activities' (UPIAS, 1976:14, my italics). Alongside terms such as "marginalisation" and "discrimination", this analysis conceptualises disability and disabling processes through nominalizations of *transitive* verbs. Hence, a

"normal" or "original" situation prior to the transition is presupposed, thereby viewing the situation in question as a negation or disabling of *what it otherwise would have been*. This testifies to a deeply problematic tendency within disability research: when empirical research finds differences between the lives of disabled adolescents and the social mainstream, these differences will often be interpreted as symptoms of exclusion. In this way Giddens (or other modernization theorists, like Zygmunt Baumann or Ulrich Beck) remain an *implicit counterbalance* to large areas of disability theory.

This counterbalancing has led research to focus on 'normal' practices, which are assumed to take place *with or without* the disabled adolescents. A significant danger may be inherent in this: research can, in its eagerness to investigate how young people are excluded from particular locations, under-interpret and under-communicate what they actually do in places where they actually are.

The purpose of this research paper is to nuance this conflict by interpreting the rich data of a single-case study. Based in the field of sociology, but aimed at an interdisciplinary research community, a double argument is presented. On the one hand, disabled young people are subjected to serious and deep-seated barriers, which fit very badly with Giddens' examples. On the other hand, their experiences cannot be reduced to symptoms of exclusion. On the contrary, analysis of reflexivity and flexibility in late modernity can be very beneficial to our understanding of these experiences. Furthermore, this relationship is in fact mutually fruitful.

Data and method

This article is a case study, exploring a confrontation between sociological theories and case data. This requires a twofold approach. On the one hand, Giddens' "sociological narrative" is compared to the agency presented in the case data. On the other hand, the discrepancies produced in that comparison are used to discuss sociological disability scholars' critique of modernization theory. The actual case can be described as follows:

Nina (15) has a serious but non-progrediating neurological impairment. She needs a significant degree of assistance in her everyday life, both within and outside her home. She lives together with her parents and her younger brother. Her family – her father (an engineer), her mother (a health care assistant), Nina and a nine-year old brother – is a typical middle-class Norwegian family. They live in a detached house in a suburban neighbourhood.

The data comprises transcripts (made by a professional and independent firm) of two individual in-depth interviews, one with Nina and another with her mother. The semi-structured interviews, each about 90 minutes in length, were conducted in the informants' homes. The interviews were conducted by the researcher, as part of a PhD project entitled *The future belongs to hope and worry* (2005–2010). The informants were asked to describe some everyday situations, and how they envisioned similar situations approximately 15 years into the future. To ensure that the data would contain their personal views, even though the informants agreed that the data could be analysed together, the two interview situations were strictly separated.

Alongside the verbal dimensions, the entire experience of the interview situations is included into the material. This means that 'holes' or 'gaps' in the interviewees' narratives will inform the analysis in terms of 'mute narrative' (Pytko, 2007). Hence, the interpretative scope reaches beyond explicit *discourse*. On the contrary, different *stories* are reconstructed through the interpretations, even if they are told only in part (Chatman, 1980:15–37).

This reconstructive approach includes a strong interest in how they told (or voiced) their stories. This interest is met by transcribing the interviews in full detail. However, the analytical aim is not to scrutinize discursive patterns, nor to identify the "ideological" *je ne* dimensions of the socially exclusive process that Mike Oliver terms 'disablement' (Oliver, 1990). The analysis remains somewhat "naive" *vis-à-vis* the text material, in order to gain insight into the everyday spatial practices. Hence, the practices are assumed to be just as described.

Disabled adolescents' lives are strikingly different from the mainstream, but also from one another. Hence, this single-case study requires methodological modesty. Nevertheless, it is argued that the

singularities of this case can inform discussions on grand or mid-range levels, even if such theories are not the main subjects.

Public and private space

School is a key space for most European adolescents. While many European countries have provided disabled children and adolescents with segregated education, Norway has educated most children and adolescents with impairments in mainstream schools for at least 20 years, making it a remarkable "including" policy in an European context (Vislie, 2003: 26–28). Indicative of the even greater inclusion in recent years, Nina attends the local public school less than 1 km from her home (Utdanningsdirektoratet, 2009). However, inclusion in the school space does not guarantee social inclusion. Hence, an accurate analysis of spatial practices must distinguish between 'space' and 'place'. According to the American philosopher Edward S. Casey, space is understood as 'the encompassing volumetric void in which things (including human beings) are positioned', while place is defined as 'an arena of action that is at once physical and historical, social and cultural' (Casey, 2001:683).

Disability scholars from several disciplines have noted that school practices – learning processes, physical activities, etc. – may turn school into a place of exclusion (Simeonsson et al., 2001). This is not the case with Nina. On the contrary, both she and her mother are satisfied with the school services, especially with Nina's form teacher who, according to Nina's mother, has 'only seen the possibilities and not the limitations'.

However, the "placeness" of school is not limited to education as such, it is also an important – if not the most important – place for peer interaction and peer inclusion. In Nina's account, school is a place for such inclusion, but only in a limited sense:

'I do have friends at school. My classmates are of course my friends, but they're not like free-time friends, if you know what I mean'.

The interaction-taking place, which often facilitates free-time interaction outside the school space, does not play this role in Nina's life. This is also confirmed by her mother: 'Nina has really benefited, she has come out of herself and has got good grades, but of course, social life – there are not many who come and ring on the doorbell'.

To ring a doorbell can be interpreted as connecting domestic and public space; when one rings a doorbell, that action is made possible by leaving one's own home for a public space. Standing literally *on the threshold*, one either leaves public space for a friend's domestic space, or brings the friend along into the public space. While included in the school 'space', Nina is excluded from many of the practices that make school an important 'place'.

This is also a matter of service provision and disability. Unable to get to school on her own – due to impairments, as well as inaccessible public transportation – Nina goes to school by special transport. This service provision consists of pre-arranged transportation, with home and school as the only possible destinations, and peers are not allowed to accompany the users. This excludes Nina from an important "intersection" between school space and public space: the school route. On the way to and from school, public space becomes the place for unorganised, very temporary interaction away from adult supervision. Hence, this "place" is sought after by many children and adolescents (Mitchell et al., 2001).

This spatial exclusion is not only a matter of service structure (pre-arranged transport from A to B to A), but also of service amount. The provision levels of 2010, which have been index-adjusted since the interviews took place in 2006, limit free-time transportation to 8600 NOK (approximately 1100 euros) per year. For wheelchair users, such as Nina, this amounts to an approximate total of 24 one-way transportations per year, or *one* two-way trip per month.[1]

To attribute Nina's lack of peer interaction with *free-time friends* to her exclusion from the public *spaces* would nevertheless be simplistic. Nina's absence from this "place" also is a matter of disabling social mechanisms, of which she is reluctant to speak. The state has provided her with a permo-

[1] A comparison of ten likely travel routes within Nina's county, from her residential area to the nearest cinema, to the nearest beach, etc., gave an average of 370 NOK per one-way transportation.

bil (electric wheelchair for outdoor use) that can make her partly independent of special transport. Nevertheless, she reports that she does not use this in the winter 'because that's just how it's been'. Just as almost none of her peers "ring the doorbell", she does not feel inclined to seek public space. The exclusion in this becomes clear when she is asked to describe what she expects of future friends (15 years into the future). In a modest and surprisingly low voice, she replies:

I envision myself having a few more friends than I have now, a little bit better friends than I do. I do.

The expression *a little bit better* testifies to a subtle exclusion, even more so as the last "I do" exposes a vision in need of assertion. Even though she does not expand on this, something is being said about the relationship between Nina and her peers: Without "free-time friends", Nina is simultaneously excluded from the category of *good friends*.

To grasp the spatial aspects of this, we must conceptualise the "normal" spatiality of being "good friends" or "free-time friends". As the British geographer David Sibley has demonstrated, almost all public spaces, urban or rural, are excluding to children and adolescents (Sibley, 1995). Hence, many adolescents *cross borders* in order to find, or constitute, places outside the oppressive governing that dominates public space. Hence, peer interaction is characterized by an unpredictable flow rather than planned and predictable places. For Nina public space is an important place for transportation and some pre-arranged activities, but it is hardly a place to just *hang about*. Hence, the outdoors remains an impoverished and excluding place to her, even if public or familial services make the space itself slightly more accessible.

Enriching domestic space

The story of Nina's upbringing is to a great extent one of powerlessness and exclusion. Hence, the home is often a place of protection: the family means, as Nina's mother puts it, a 'protected environment'. It is, however, equally a story of what the sociologist Bennedichte Rappana-Olsen has called the family's 'facilitating of dignity' (Rappana-Olsen, 2001). This study, which applies both to Nina's concrete opportunities and to her and others' impression of value, can be seen as resistance against exclusion. This emerges particularly clearly in her mother's story, which frequently describes a project to equip her daughter for a life containing barriers:

I have not been bitter a single day for having a child with such substantial disabilities. My goal has been to make her as strong as possible and to ensure that she is ready to tackle the challenges that will come in due course.

On one level these are practical narratives about work to minimize disability. In earlier years, this work was often concerned with impairment, training and motor development. In later years, the familial facilitation of dignity (including plans and preparations for the future) has a clear focus on practical and physical barriers:

Interviewer: Could you say a little about that too, how it is, what it is that you're speaking of? One thing is that you don't talk so much with them [the parents] about the future, but what is it that you choose to discuss with them, about the future, and what do you choose not to discuss?

Nina: Er . . . so what we discuss is houses and cars and. . .

Interviewer: Practical things?

Nina: Yes, that's what we talk about most.

Interviewer: Yes, technical aids and so on?

Nina: Yes.

Closeness is however an equally fundamental issue. When Nina's mother talks about her family, the first thing she does is to emphasize the closeness and richness of relationships within the family: 'we are closely in touch with the two girls who [Nina's father] had from earlier. They have lived partly with us through the years, and we are still in contact, so Nina has in that sense a big [family]. . .'.

This empowering focus on closeness and practical *cooperation* may exclude issues, which are one's own, and not "solvable", i.e., emotional or existential issues, from the family's communication. As to the possibility of discussing such issues with her parents, Nina is explicitly reluctant: 'that kind of other stuff I keep to myself or talk to my best friend about'.

In spatial terms, however, this *talking to my best friend* also enriches the domestic space. Nina's mother speaks explicitly about this:

Nina has a friend in the same class. And that's good, and they get on well. Nina can't go to visit her, but that's the way it is, she comes here and they spend time here and go out together.

When 'they spend time here', this is generally connected to a specific space: Nina's room. As one might expect, this is the place for friendship – "where it happens". From a disability studies viewpoint, it is interesting to note that this physical space is clearly not designed to maximize practical independence. In fact, the amount of technical aids is very low, and seems to presuppose some degree of familial assistance. This could be seen as an example of pervasive barriers. Most of all, however, it demonstrates how this room is an important and dignifying place by way of friendship and familial support, rather than by material structures.

The enriched domestic spaces – and places – of the future

While the present domestic space is described in a positive way, there seem to be more worries (and less language) about *future* domestic space. This emerges not least in Nina's mother's worries about life *away from home*: Mother: Yes, and it's obvious, the threshold for accepting help as well, when one has a disability. They will, when they first move away on their own, they have to look after themselves and. . .

Worries like this may be interwoven with a social pattern identified by the social researchers Nicola Hendey and Gillian Pascall (2004:166): disabled adolescents 'achieve employment, economic independence, personal autonomy, independent housing and citizenship to a lesser degree and at a later stage than non-disabled adults'. This 'extended period of transition' may be interpreted a "compensation": an effect of, or a response to, the lack of inclusion in public space, or what Hendey and Pascall call 'a largely hostile context' (2004:181).

This notion is certainly in line with both Nina and her mother's images of the future. When they envisage the future in terms of 'lots of contact with the family', this indicates an important hope: they hope to enrich the domestic space in her future home in a somewhat similar way to her current domestic space. When asked about this specifically, Nina envisages that her own future family may well come to live in the same house (or at any rate in the same neighbourhood) as her parents. In Nina's words: 'We have spoken about extending this house so that I get my own flat here in the house. And that I will have my own entrance to the house. But it hasn't. . . It's only an idea as yet'. This is conceptualised as facilitating of close relations within the family, but also as an answer to barriers and practical challenges. As Nina puts it:

When it occurred to Mum and Dad that we should perhaps build an extension so that I could have my own flat, I thought it was great, because that way I wouldn't need to have new people round all the time. . . I'll have that anyway, so that I have Mum and Dad easily available if I need them and things.

If the close and caring home environment will be carried forward, this is not primarily a source of protection, but even more of strength and freedom. The family's future role is about more than enriching domestic space. It is also envisaged that familial relations can facilitate dignity and freedom in public space. This issue emerges perhaps most clearly when Nina is explicitly asked to narrate "a dream" for the future:

Nina: Yes, yes, err, I get what you mean. That is, I would really like to, but I'll perhaps manage it when I'm a bit older, to go to the States all by myself.

Interviewer: Like, just you?

Nina: Yes, and to visit my sister.

This is a plan to travel 'all by myself' – but it is also a plan that the public space *in the States* should be a family-centred place. Thus family proximity becomes a matter of experiencing the world. Even this project involves a family element, primarily the joy of close relationships and reunions, but perhaps also social safety and practical assistance.

While practical issues may be foregrounded in these narratives, the tone and narration testifies to mutual support and strong emotional connections. The tentative manner of speaking, which can only just be perceived through the transcript, is full of emotional intensity and thoughtfulness. Linguistically, this is indicated by the mother's use of the pronouns *we* and *us*, which is pervasive even

when referring to the future. When she returns to her wish to lay a good foundation for her daughter's future, this project in a sense includes the whole family: 'it has been my driving force up through the years that we have to fight a bit and that we have to keep at it to get the best possible outcome'.

Barriers to doing, being and voicing

To understand disabling social barriers, the British sociologist Carol Thomas distinguishes between 'barriers to doing' and 'barriers to being' (Thomas, 1999). According to her, disability barriers always involve "'restrictions" within ourselves [which] place limits on our psycho-emotional well-being' (Thomas, 1999:47). A lack of interaction (doing) leads not only to frustrations (reactions to barriers) but also to a kind of vacuum in terms of self-image and identity.

While the family's facilitation of dignity is successful *vis-à-vis* such barriers, this success has spatial limitations. With regard to *doing*, familial support facilitates integration in public space, and peer placeness with domestic space, but hardly any place for familial *dis-integration*. Even if the familial support gives Nina *freedom from* some disabling barriers, it does not give *freedom to* actions that are incompatible with the family. For instance, these life strategies are not suitable for *secrets* – a teenage life regulated by familial spatiality or public transport is hardly the place for unaccepted sexuality, drug abuse or resistance to socio-cultural norms. In an adolescent context, this can itself be a barrier.

We have already seen that barriers to being – that is, being happy, being important in others' lives, being protected and supported – are connected to public space, hence the enriching of domestic space. Such barriers are not only an "inner phenomenon", but also a matter of language, expression and communication, of what one might call barriers to *voicing*. In this case, the ability to tell seems connected to issues regarding the enriched domestic space, rather than to those regarding public space. Both Nina and her mother have a significant verbal mastery when speaking of family life and home-based activities. When speaking of peer groups, leisure and public space, however, their language becomes remarkably incomplete, groping and tentative: the discourse is coloured by 'I don't know', 'it's kind of like this', and similar phrases.

In particular, such barriers make it hard to think, feel or voice the future. This is evident in both the mother's and Nina's images of the future. A powerful and significant example – which also demonstrates the crucial interplay between all these kinds of barrier – is the question of whether or not Nina will have children of her own. When Nina's mother speaks of this, it is a *difficult* narrative. This story, dealing deals with issues of future health, practical and social difficulties, is itself difficult to tell:

Mother: No, but getting it, it . . . no, it . . . now I'm being absolutely truthful. This business of children is in fact the most difficult question. I have thought about it. We've never discussed it, Nina and I. It's just what I've thought within myself, that having children, it's not. . . But at the same time, I'm not going to take it away from her, I should say, the joy of having a child, because I think something else, it's that it's. . .

Interviewer: Yes, demanding business.

Mother: Yes, it is. And I'd say, after all she also could have a child with a disability, and that's even more demanding when you. . . But you then depend on the partner you have. You're not going to have that child on your own, hopefully, so obviously, lots of things may be in place so that. . . And then there's the body, what goes on inside the body, is the body in a state to. . .

[. . .]

Yes, there are lots of people with ruptured spinal chords who have children, but what will it in a sense . . . yes, do to her, what will it cost. . .

Even though her mother is clear that this is 'in fact the most difficult question' and the transcript manages up to a point to convey the uncertainty and 'discursive vacuum', it does not manage to convey fully either the intensity or the weight of seriousness. Her mother's manner of communication – particularly the body language and the tone of voice used in this narrative – is markedly different from the rest of the interview. From serious and sometimes concerned, but above all warm and reflective tone in the rest of the interview, the tone here is far more painful. Nina's mother is in every sense *moved*, even having tears in her eyes, when she speaks about this.

This issue – which has yet to be shared or discussed within the family – is voiced by Nina in a similar tone of voice: more serious, slower and more emphatic. At the same time she lowers the volume a

notch, as though this were literally not to be discussed out loud. While this may be a response to social barriers, including the barriers inscribed in her mothers image, Nina is not muted or at a loss for words. To the contrary, her language is at its most reflexive at this point of the interview, discussing an unspoken and very difficult issue.

Furthermore, Nina's image of her possible future motherhood is clearly different from that of her mother:

I envisage that it can be pretty tiring, but that it's a good thing, and that it's fun.

[. . .]

We have, after all, been babysitting some [children]. I have two sisters. And one of them has two little ones. One of them is three, and the other one just turned one. I like having them around me. So . . . then. . .

Despite her expectation that it would be 'pretty tiring', she retains a positive image overall. Furthermore, the very colloquial interjections in her statement suggest several narrative presuppositions. In the Norwegian original, the second sentence is especially important in this respect: 'Vi har jo passa noen.'. The Norwegian word *jo* (here translated, a bit too explicitly, as 'after all') positions her statement as a *response*. It is likely that she in some way is responding to worries, be they her own or ones that she has sensed in familial (non)communication.

This time axis arguably has an additional stage, suggesting a narrative of contemplation. The end of the statement, 'So . . . then. . .' indicates a point of contemplation or summarizing in the aftermath of an initial response. Thus it seems as if Nina envisages motherhood as 'a good thing' *all things considered.* This way of speaking, or thinking, is reflexive rather than idealizing.

Disabled motherhood is a very unlikely subject among Nina's peers, almost absent in cultural representations of motherhood, and clearly not discussed in her family, When Nina still voices this in such a reflexive and even semi-argumentative manner, our analysis should not give total primacy to issues of social barriers. Just as with the everyday practices, Nina's voicing demonstrates she is not just *subjected to* disabling barriers. While she is vulnerable, and often *alone* with certain issues, it is necessary to acknowledge the joy, valuing and freedom that are achieved, both by Nina herself and within her family. To understand agency within disabling barriers, this agency must be conceptualised as active, reflexive and competent.

Discussion: youth, disability and ideal-typical modernization

Giddens can certainly be accused of misrepresenting, or even forgetting, the lives of disabled adolescents. However, this scarce (or lacking) discussion of disability can be attributed to his analyses' reliance 'on ideal-typical procedures' (Giddens, 1991:2). This term is also crucial to Hughes' critique. While he has argued the relevance modernisation theory elsewhere (Hughes, 2002), he argues than Giddens' ideal-typical descriptions of youth and adolescence makes the signifiers "youth" and "disability" incompatible (Hughes et al., 2005:12).

'Ideal-typical' is a potent terminological interface between Giddens' and Hughes' work. In different ways, both seem to define ideal-typical as representative. It is this notion that allows Giddens to argue that the lacking focus of disability was a cost in identifying 'some structuring features at the core of modernity' (Giddens, 1991:2). Similarly, Hughes' dismissive argument – that the ideal-typical descriptions 'of youth, as a desired attribute of identity, implies the erasure or transcendence of anomaly' (Hughes et al., 2005:12) – presupposes that such descriptions claim to be fully representative.

Interestingly, this is contrary to the oeuvre where the term was developed: the work of Max Weber. Weber defines the ideal-type as:

> It is a conceptual construct, which is neither historical reality nor even the 'true' reality. It is even less fitted to serve as a schema under which a real situation or action is to be subsumed as one *instance*. It has the significance of a purely ideal *limiting* concept with which the real situation or action is compared and surveyed for the explication of certain of its significant components. (Weber, 1949:3, original emphasis)

In Weber, the ideal-type is not meant to be representative (as Giddens seems to suggest). Neither are everyday lives of any individual to be subsumed under it (as Hughes sees to suggest). Instead, an ideal-type is a *Gedankenbild* (here translated as 'conceptual construct') with which one can *think* actions and situations, without *identifying* them with the ideal-type.

While Giddens' and Hughes' uses of 'ideal-typical' sets them apart, a more Weberian turn on this interface may give fruitful opportunities between modernization theory and disability studies. To demonstrate this, one key finding (Nina's plans of having a family life in an extension of her childhood home) will be reinterpreted.

Firstly, Nina's life and strategies can shed light on dis-embedding on a broader scale. Even if Giddens uses "representative" examples, he himself views dis-embedding as a difference within a *current* ("normal" or habitual) social order. Amongst the urban, 'ethnically Norwegian' middle-class of 2006, plans for the future are often ordered (or focused) around *one's own home*, clearly removed from the childhood home. Unlike those who do (positively re-enforcing this habitual order), or regret that they can't negatively (re-enforcing it), Nina and her mother seems to frame this plan as something that would *work for them*. This is, in a cultural sense at least, clearly dis-embedding vis-à-vis the habitual order.

Secondly, expectations "normally" associated with *one's own home* are not discarded or disavowed. On the contrary, the roles she otherwise would have planned for – i.e., as a mother, lover and friend – are envisioned and emphasized, only in other contexts than one would expect. While the plan is dis-embedding (providing freedom from social barriers), it is also re-embedding in the sense that *freedom to* is envisioned in unusual places: freedom to have a family life, to have guests, to be a lover and a mother.

This does not deny that social barriers may have influenced this plan. The case data provides insights into the "impact" of disabling barriers, insights that fundamentally presuppose ontrafactual or constructionist claims (life *without* disabling barriers would have been different). Rather, the point is that this contrafactual insight can come to exclude another (life *within* disabling barriers could have been different).

In this context, the modest role of this case study is quite simple. On the one hand, it demonstrates how ideal-types from modernisation theory can bring into light important aspects of a disabled teenager's life, even if the *image* in the ideal-typical description seems irrelevant or even discriminatory. On the other hand, disability studies indicate a potential for modernisation theory: if variance, reflexivity and complexity is typical of late modernity, a lot would be gained by turning the empirical focus towards social agents comparable to Nina: "a-typical" agents living – and planning – "a-typical" lives.

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